



NEWBORN SCREENING FACT SHEET

POSITIVE HEMOGLOBINOPATHY SCREENING RESULT FOR SICKLE CELL DISEASE

WHY DO WE SCREEN BABIES FOR HEMOGLOBINOPATHIES?

Hemoglobin is the chemical inside of red blood cells that carries oxygen. If there is something wrong with this chemical, many problems may arise. In the case of sickle cell disease, babies may get infections that are life threatening. It is important to find out which babies have this disease so they can get medical attention early and this risk of infection is made as low as possible.

WHAT DOES A POSITIVE SCREENING TEST RESULT FOR SICKLE CELL DISEASE MEAN?
This test result means that the hemoglobin that causes sickle cell disease was found in your baby's blood.

HOW CAN SICKLE CELL DISEASE AFFECT YOUR BABY'S HEALTH?

Sickle Cell Disease is a life-long condition that can cause severe anemia, stroke, lung and kidney damage, and painful crises. Children with Sickle Cell Disease are at risk for serious infection and need to take antibiotics to prevent infection. It is very important that these antibiotics start as early in life as possible.

WHAT SHOULD A PARENT DO WITH THIS TEST RESULT?

A test result indicating only the presence of sickle cell hemoglobin may mean that your baby has sickle cell disease. In order to be sure, you and your doctor need to discuss the test results and to obtain confirmatory testing for your baby. Babies with Sickle Cell Disease need to take antibiotics to prevent infection.

WHO CAN I CONTACT FOR MORE INFORMATION?

You can obtain more information from your baby's doctor about abnormal hemoglobins and other specialists available. Genetic counseling to discuss testing options and family risks for hemoglobin problems is available through clinics at various sites around the state by genetics specialists from UNMC. To schedule an appointment, you can call (402) 559-6800 or (800) 656-3937. Specialists in Hematology are available at: James Harper, MD- UNMC (402) 559-7257; David Gnarra, MD- Children's (402) 955-3950, Howard Koch, MD-Alliance (308) 762-2125.